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Children with New Onset Seizures: A Prospective Study of Parent Variables, Child Behavior Problems, and Seizure Occurrence

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Abstract

Objective—Parent variables (stigma, mood, unmet needs for information and support, and worry) are associated with behavioral difficulties in children with seizures, however, it is not known how this relationship is influenced by additional seizures. This study followed children (ages 4 – 14 years) and their parents over a 24-month period (with data collected at baseline, 6, 12, and 24 months) and investigated the effect of an additional seizure on the relationship between parenting variables and child behavior difficulties.

Methods—The sample was parents of 196 children (104 girls and 92 boys) with a first seizure within the past 6 weeks. Child mean age at baseline was 8 years, 3 months (SD 3 years). Data were analyzed using *t*-tests, chi-square tests, and repeated measures analyses of covariance.

Results—Relationships between parent variables, additional seizures, and child behavior problems were consistent across time. Several associations between parent variables and child behavior problems were stronger in the additional seizure group than in the no additional seizures group.

Conclusions—Findings suggest that interventions that assist families to respond constructively to the reactions of others regarding their child's seizure condition and to address their needs for

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Conflict of Interest

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information and support could help families of children with continuing seizures to have an improved quality of life.

Keywords

First seizure; child behavior problems; parents; worry; stigma; need for information and support

Children with epilepsy have long been known to have higher rates of behavior problems than healthy children or children with other chronic health conditions (1-3). Early studies showed that children with epilepsy have more dependency and peer relationship problems than children with either diabetes or cardiac conditions (4) and more quality of life problems than children with asthma (5). In childhood epilepsy, behavior problems can be more obvious and pervasive than the manifestations of actual seizures, add to stigma, and increase the likelihood of child and/or family isolation. These behavioral problems experienced by children with epilepsy disorders often present unique challenges to their parents.

Studies investigating relationships between parenting variables and child behavior problems in children with epilepsy show that parent perceptions are associated with child functioning (6, 7). In one of the earliest studies, Mitchell and colleagues (8) found that negative parental attitudes were associated with child behavior problems. Cross-sectional studies exploring parental perceptions of stigma in parents of children with epilepsy also showed relationships with behavior problems. In studies of children with chronic epilepsy, Carlton-Ford and colleagues (9) found that parental perceptions of stigma were related to child behavior problems, and Dunn et al. (10) found that greater parental perception of epilepsy-related stigma was associated with relatively more child depression symptoms.

There are few prospective, longitudinal studies investigating parental perceptions and child behavior problems. Ostrom and colleagues (2, 11) investigated parent and child adaptation, including child behavior problems, in a sample of children with newly diagnosed epilepsy and a comparison group of children without a health condition. A major finding was that disruption of usual parenting practices from the onset of seizures in the child and family trouble (such as divorce) was associated with more behavior problems in the children. Children who had behavior problems before the onset of seizures were at the highest risk for behavior problems during the first year after epilepsy onset. A limitation of this study was the measurement of the family variables, which were categorized in a yes/no fashion (e.g., presence or absence of family trouble).

Studies investigating relationships between parent variables and child behavior problems over time have shown an association between parenting variables and child behavior problems (2, 8). According to Akay et al. (12) high levels of anxiety and depression found in mothers of children with epilepsy might adversely influence their attitudes toward their children. In addition, a 24-month investigation of 337 children with new onset epilepsy showed that maternal depressive syndrome had a negative effect on child's quality of life (13). Parental need for emotional support was found to contribute to later internalizing behavior problems in children with new onset seizures (14). However, no reported prospective study has explored the association of parent variables and child behavior

problems in a sample of children with a first seizure and also explored the effect of an additional seizure on that relationship.

The current prospective study builds on earlier work by measuring the effect of at least one additional seizure on the association of parent variables and child behavior problems in a sample of children with new onset seizures over a 24-month period. The purpose of this study was to describe the associations over time between parent perceptions (stigma, mood, worry, need for information and support) and child behavior problems (total, internalizing, and externalizing) and determine the influence of an additional seizure on the relationship.

We compared parents whose child experienced additional seizures with those parents whose children had no additional seizures after the initial unprovoked seizure because we have found that children with recurrent seizures had more behavior problems in our past research (15). Specifically, we investigated potential effects of seizure group (additional seizure vs. no additional seizure) and time since seizure onset (baseline, 6, 12, and 24 months) by exploring interaction effects of group and/or time with parent variables. In addition, we controlled for research site and race as well as other demographic variables that have been related to child behavior problems in past research such as child age, child gender, and socioeconomic status (16-18).

Method

Sample

This study was part of a larger study of 224 children with new onset seizures and their primary caregivers (14, 15). The larger study was approved by the institutional review boards at Indiana University and the University of Tennessee, Memphis. Of the 224 children, additional seizure information was available for 196 (88%); thus the subjects in this study were 196 children (104 girls and 92 boys) with new onset seizures and their primary caregiver. The 28 families not providing seizure information did not significantly differ from the 196 on child age, child sex, type of seizure, medication use at baseline, or education of caregiver. They did significantly differ on race ($p < 0.0001$). African Americans were less likely to remain in the study than Caucasians (32.7% vs. 7.1%). At enrollment the children were between 4 and 14 years of age ($M = 8$ years, 3 months; $SD = 3$ years) and within 6 weeks of their first recognized seizure ($M = 35$ days). Subjects were recruited through electroencephalogram (EEG) laboratories, emergency departments, and pediatric neurologists in two large children's hospitals (Indianapolis and Memphis) and from practices of private pediatric neurologists in Indianapolis.

Exclusion criteria for the larger study were: a co-morbid chronic physical disorder, intellectual disability (based on either clinic records or parent report), a sibling with a chronic condition, or seizures precipitated by an acute event (e.g., intracranial infection, metabolic derangement, and recent head injury). Children who had had two or more febrile seizures or who were placed on daily antiepileptic medication (AED) after a febrile seizure were also excluded. The rationale for this latter exclusion was that the AED might influence behavioral, emotional, or cognitive response to new onset seizures. Parental informed

consent and child assent were obtained prior to data collection. The study was approved by the institutional review boards overseeing investigations at the facilities described above.

Data were collected four times: baseline, 6, 12, and 24 months. Baseline data, which were collected within 6 weeks of the first recognized seizure, were retrospective to provide information about the 6 months prior to the seizure. Data were collected using computer-assisted, structured telephone interviews with the primary caregiver, who was the mother with very few exceptions. During the 2-year period of the study, 110 of the children had at least one additional seizure. Demographics for the children and information on AEDs are presented by the two seizure groups (no additional seizure and at least one additional seizure) in Table 1.

Instrumentation

Variables measured were: child behavior problems (Total, Internalizing, and Externalizing) and parent variables (Stigma, Positive Mood, Unmet Needs for Support and Information, and Worry). Child behavior problems were measured at baseline, 6, 12, and 24 months. Parent variables were measured at 6, 12, and 24 months, but not at baseline because some of the items on these scales pertained to seizures and the baseline data collection reflected the period before the first seizure.

Child Behavior Problems—The Child Behavior Checklist (CBCL) (19) was completed by the parent to measure the child's behavior problems during the past 6 months. The CBCL has 118 items describing behaviors that are rated using 3-point scales of 0 (*not true*), 1 (*somewhat or sometimes true*), and 2 (*very true or often true*). Parents were specifically instructed to exclude any behaviors that might have been actual seizure activity or any behaviors that occurred immediately prior to, or after, a seizure episode. The reliability and validity of the CBCL as well as norms based on age and gender have been established in past research (19). The three scores used in this study were the *T*-scores for Total behavior problems, internalizing problems, and externalizing problems. These *T*-scores are normed for age and gender. The internalizing problems score includes syndrome scale scores of anxious/depressed, withdrawn, and somatic complaints, and the Externalizing Problems score includes the syndrome scale scores of delinquent behavior and aggression. Social, thought, and attention problems scores are included in the total problems score in addition to internalizing and externalizing problems scores.

Parent Variables—Stigma was measured using a 5-item scale developed for the study (20). Parents rated their perceptions of stigma related to their child's seizure condition on 7-point scales of 1 (*strongly disagree*) to 7 (*strongly agree*) with a higher score reflecting more perceptions of stigma. Coefficient alphas were good, ranging from .76 to .83.

To measure Positive Mood, parents were asked to rate how strongly they felt on each of 10 affective adjectives (e.g., happy, sad, calm) when they thought about being a parent of a child with a seizure condition. Parents responded on 7-point scales of 1 (*do not feel at all*) to 7 (*feel very much*) with a higher score reflecting a more positive mood. Internal consistency reliabilities were very good, with coefficient alphas ranging from .83 to .84.

Unmet Needs for Support and Information and Worry were measured using The Parent Report of Psychosocial Care Scale (21). The unmet needs subscale has 14 items that measure the extent to which parents need either emotional support or information related to parenting a child with seizures. Parents respond on 3-point scales from 1 (*no need for information or help*) to 3 (*strong need for information or help*) with a higher score reflecting greater need. Coefficient alphas were .95 at each time point. To measure parent Worry related to the child's seizure condition, parents were asked to respond to five items on 4-point scales: 1 (*not at all*), 2 (*somewhat*), 3 (*moderately*), and 4 (*very much*). A higher score reflected more worry about the child's seizure condition. The internal consistency reliability was very good with coefficient alphas ranging from .83 to .84.

Statistical Methods

Baseline variables were compared between the additional and no additional seizure groups using *t*-tests and chi-square tests. Repeated measures analyses of covariance were conducted to examine the association of parent variables and child behavior problems after adjusting for any additional seizure during the 24 months after the first recognized seizure (yes/no), visit, child age, unrecognized prior seizures (yes/no), site, child gender, race (African American, Caucasian, other), education of primary caregiver (as a surrogate for socioeconomic status), and a time-varying covariate for AED use within the 3 months prior to each data collection point. Three different interactions were investigated and not found to be statistically significant. Therefore, they were omitted from the final models. The three omitted interactions were: 1) associations between parent variable and additional seizure and behavior across visit (parent variable-by-additional seizure-by visit interaction term); 2) associations between additional seizure and behavior across visits (additional seizure-by-visit interaction term); and 3) associations between the parent variable and behavior across visits (parent variable-by-visit interaction term).

The association between the parent variable and behavior between children with and without additional seizures (parent variable-by-additional seizure interaction term) was also investigated. If it was significant ($p < 0.05$), it was kept in the final model and slopes were estimated for each seizure group. If it was not significant, it was removed from the final model. For each outcome, it was assumed that the correlation between all pairs of repeated measures was identical (i.e., compound symmetry). We also assumed a missing-at-random mechanism for the outcomes. That is, controlling for covariates, missingness is not related to the value of the outcomes, so that the reported effects are unbiased estimates. Over all study follow up visits (potential $n = 196 \times 3 = 588$), missing data on any study variable was minimal (analysis $n = 564$ for stigma, 557 for mood, 563 for unmet needs, and 565 for worry; range of only 3.9% to 5.2% missing).

Results

Descriptive Statistics

Out of the 196 children, 185 (94.4%) had all four visits. Ten children had 3 visits and one child had 2 visits. Baseline descriptive statistics by additional-seizure group are shown in Table 1. There were no significant differences on any of the demographic, behavior, or

parent variables between the two seizure groups at baseline. At the time of the first interview, 54.6% of the children had been placed on AEDs. Specifically, AEDs were being used in 50.9% of the children who experienced additional seizures and 59.3% of the children who did not have an additional seizure. Information about AED use was available at all interviews in 88.8% ($n = 174/196$) of the children. In the group with data at all interviews, 31.0% were never on AEDs, 41.4% were always on AEDs, and 27.6% were on AEDs at some but not all data collections.

At baseline, parents reported behavioral problems scores that were slightly higher on average, but less than one-half standard deviation from the established *T*-score norms of 50. The six-month descriptive statistics for parent variables are shown in Table 2. In general, parents of children in the additional seizure group reported higher perceptions of stigma (average of 2.96 vs. 2.07), lower positive mood (average of 5.12 vs. 5.73 on the 7-point scale), greater unmet needs (both groups indicating that there was ‘some need’ for information on average), and greater worry (somewhat vs. not at all worried on average), than parents of children in the no additional seizure group.

Association between Parent Variables and Child Outcomes

Model results indicating whether the parent variable-by-additional seizure interaction or only the main effect for parent variable was significant (along with relevant estimated partial slopes) are reported in Table 3 by behavioral outcome, and within each behavioral outcome, by parent variables.

Parent Variables and Child Total Behavior Problems—Higher parent worry scores were significantly associated with higher total child behavior problems scores ($p < 0.0001$) with all associations being consistent between the two seizure groups. The strength of the associations of stigma, positive mood, and unmet needs for support and information with total behavior problems scores differed between the two seizure groups (parent variable-by-seizure group interactions: $p = 0.0016$, $p = 0.0008$ and $p = 0.0002$, respectively). Higher parent perception of stigma, lower positive mood scores, and higher levels of unmet needs for support and information were associated with higher total behavior problems scores among children with additional seizures, but not among children with no additional seizures.

Parent Variables and Child Internalizing Behavior Problems—Higher parent worry scores were significantly associated with higher child internalizing behavior problems scores ($p < 0.0001$) with the association being consistent between the two seizure groups. The strengths of the association of parent perceptions of stigma, parent positive mood, and parent unmet needs for support and information with the internalizing problems score differed between the two seizure groups (parent variable-by-seizure group interactions: $p = 0.0326$, $p = 0.0001$, and $p = 0.0001$, respectively). For the additional seizure group, higher parent perception of stigma, lower parent positive mood scores, and higher parent unmet needs for support and information scores were associated with higher child internalizing problems scores. These associations were not statistically significant in children with no additional seizures.

Parent Variables and Child Externalizing Behavior Problems—Lower parent positive mood scores ($p < 0.0001$) and higher parent worry scores ($p = 0.0004$) were associated with higher child externalizing behavior problems scores. Both associations were consistent between the two seizure groups. The strength of the associations between parent perception of stigma and parent unmet needs for support and information and child externalizing behavior problems differed between the two seizure groups (parent variable-by-seizure group interactions, $p = 0.0408$ and $p = 0.0029$, respectively). Higher parent perception of stigma and higher parent unmet needs for support and information were significantly associated with higher child externalizing problems scores in the group with additional seizures but not in the group of children without additional seizures.

Discussion

In this prospective study of children with a first recognized seizure, relationships between parenting variables and child behavior problems were investigated over a 2-year period to determine the effect of additional seizures on relationships between parent and child variables. All associations between parent and child variables were in the expected direction and were stable over time between the two seizure groups (additional seizures versus no additional seizures). Differences by additional seizure group were noted in several cases. In families of children who had additional seizures, greater parent perception of stigma associated with epilepsy, more negative parent mood related to having a child with epilepsy, and more unmet needs for information and support were associated with more total child behavior problems compared to the families whose children experienced no additional seizures.

Our findings suggest that interventions that assist families to respond constructively to the reactions of others regarding their child's seizure condition and to address their needs for information and support could help families of children with continuing seizures to have an improved quality of life. These suggestions are consistent with those reported by others. For example, Nguyen et al. (22) recommend practical strategies to minimize stigma and worries, and Gazibara et al. (23) maintain that epilepsy knowledge among parents had a profound role on parental self-perceptions and their relationship with the child. According to Rodenburg et al. (24), seeking information lowers parents' stress level. Finally, participants in a study by Nguyen et al. (22) found information seeking to be empowering because it improved their understanding of seizure scenarios and increased their sense of control over the situation.

It is notable that relationships between parental worry and child behavior problems scores were not significantly different between the two groups at any time. Although this finding may appear counterintuitive, it is congruent with findings in other prospective studies. Ostrom and colleagues (11) found that parental factors, including disruption of usual parenting practices during the period of time between the occurrence of seizures and the receipt of a diagnosis, to be the most consistent factor associated with child behavioral functioning. Similarly, Mitchell and colleagues (25) found that good seizure control in the child was not associated with cessation of anxiety in the parents. Rather, higher levels of parental anxiety were related to socio-cultural variables. Increased parental anxiety was

associated with protective attitudes toward the child in the study by Mitchell and colleagues, which could lead to, or be a result of, child behavior problems.

Our findings indicated that parental worry was associated with more child behavior problems over time regardless of whether the child had an additional seizure or not. The finding that parent worry can influence child behavior is consistent with an earlier study by our research team. We found that caregiver anxiety moderated change in child language cognitive functioning and writing achievement, with children having worse achievement when their parents were more anxious (26). These results indicate that families of children with new onset seizures should be assessed for worry about their child's seizure condition as well as their own needs for information and support. Asking parents specifically about their worries and identifying their needs for information and support would provide important information to guide interventions that have the potential to reduce family distress. A recent study showing that child and adolescents are more likely to learn anxiety behaviors from their environment rather than from genetic transmission also provides empirical support for addressing parental worry (27).

Although statistical analyses cannot fully capture the reciprocity inherent in family relationships (28, 29), the associations between changes in parent variables and child behavior problems were in the expected directions. That is, less adaptive parent variables were accompanied by more child behavior problems over the 24 months of the study. In addition to the advantages of the longitudinal design, the study addressed several other weaknesses present in the child chronic disease literature described by Drotar (30). The participants in our study represented different geographic areas, ethnic groups, and socio-economic backgrounds. However, in our study African Americans were less likely to provide data after baseline and therefore were less likely to be represented in this longitudinal study. According to Blumenthal, African Americans are reluctant to serve as research subjects, especially when researchers are from different cultural, racial, or ethnic groups. In our study interviewers were primarily white and from a different region of the country, which might have affected retention (31). As a result study findings are not relevant to families of ethnic minorities. Future research should explore relationships between parent variables and child behavior problems in children with an epilepsy disorder from samples that are large enough to allow for study of relationships within ethnic minority families.

Another limitation was that data were primarily supplied by one family member (i.e., the mother). Collecting family data from mothers is common in family studies because mothers are more likely than fathers to bring children to the health care setting. However, collecting data from only one family member might not capture a full picture of family processes related to the child's health condition. Future studies may benefit from focusing on both mother and father response and family problem-solving related to the seizure condition (30).

Our findings showing a stronger relationship between parent need for information and child behavior problems when children have an additional seizures point to the need for repeated assessment and intervention pertaining to child behavior and family dynamics following the onset of seizures. Another study showed that although psychosocial care needs were highest at 3 months, they remained relatively high over the first 24 months (32), which suggested

that family education about seizures is needed throughout the first 24 months. Assisting parents to regain their normal state when the child has an epilepsy disorder may help to restore a sense of mastery and promote both family functioning and improved child behavior.

Summary and Conclusions

Although several associations were significantly stronger between parent variables and child behavior problems in the additional seizure group over time, the two groups (seizures vs. no additional seizures) had many similarities. Families whose children continue to have seizures appear to have needs that may be addressed by the provision of information about the epilepsy disorder and its management. In fact, Gazibara and colleagues (23) suggest that ensuring education and support for both parents and their children with epilepsy should be the principal goal of health care services. Continued assessment of parental needs for information and support and worry is indicated. In addition, a structured assessment guide might yield more specific information than one or two broad questions directed at the parent or caregiver. Further studies are recommended to develop effective and efficient assessment instruments and interventions to address the needs identified.

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Highlights

- Parent stigma was more strongly associated with child behavior problems when the child had an additional seizure.
- Parent mood and need for information and support were more strongly associated with child behavior problems when the child had an additional seizure.
- Greater parent worry was associated with child behavior problems in children with or without an additional seizure.

Table 1

Demographic and Clinical Characteristics at Baseline

Baseline Characteristics	No Additional Seizures (n=86)		Additional Seizures (n=110)		
	Mean	SD	Mean	SD	p-value
Child Age (years)	8.13	3.09	8.36	2.90	0.6068
Caregiver Education (years)	13.93	2.50	13.84	2.66	0.8017
Gender - % Female	53.5%		52.7%		0.9156
Race					
% Caucasian	86.0%		75.5%		0.1074
% African American	10.5%		21.8%		
% Other	3.5%		2.7%		
Main Seizure Type					
% Generalized: Tonic-Clonic	44.2%		34.5%		0.2318
% Generalized: Absence	4.7%		13.6%		
% Simple Partial	9.3%		6.4%		
% Complex Partial	22.1%		27.3%		
% Generalized: Atonic, Akinetic, Myoclonic	0.0%		0.9%		
% Partial seizures evolving to secondarily generalized	18.6%		14.5%		
% Unclassified	1.2%		2.7%		
Medication usage - % taking AEDs	59.3%		50.9%		0.2415

Table 2

Child Behavior and Parent Variables

	No Additional Seizures (n=86)		Additional Seizures ^a (n=110)		
Child Problem Scores at Baseline	Mean	SD	Mean	SD	p-value
CBCL Total Problems T-score	54.34	9.96	56.79	10.06	0.0904
CBCL Internalizing Problems T-score	52.16	9.39	54.33	10.47	0.1349
CBCL Externalizing Problems T-score	52.83	11.33	54.00	10.33	0.4499
Parent Variables at 6 Months					
Stigma	2.07	0.96	2.96	1.36	<0.0001
Positive Mood	5.73	1.10	5.12	1.30	0.0007
Unmet Needs for Support and Information	1.55	0.47	1.96	0.59	<0.0001
Worry and Concern	1.33	0.54	1.64	0.73	0.0010

^aChildren in this group had at least one additional seizure within 24 months after the initial seizure.

Table 3Estimated Partial Slopes^a from Repeated Measures ANCOVA Models

	Total Behavior Problems	Internalizing Problems	Externalizing Problems
Parent Variables			
Stigma	Stigma*AS ^b $\beta_0 = 0.26; \beta_1 = 2.13$	Stigma*AS $\beta_0 = 0.72; \beta_1 = 2.08$	Stigma*AS $\beta_0 = 0.18; \beta_1 = 1.43$
Positive Mood	Positive Mood*AS $\beta_0 = -0.32; \beta_1 = -2.27$	Positive Mood*AS $\beta_0 = -0.38; \beta_1 = -2.72$	Positive Mood $\beta = -1.23$
Unmet Needs for Support and Information	Unmet Needs*AS $\beta_0 = -0.51; \beta_1 = 4.29$	Unmet Needs*AS $\beta_0 = 0.08; \beta_1 = 5.30$	Unmet Needs*AS $\beta_0 = -0.86; \beta_1 = 3.11$
Worry	Worry $\beta = 2.72$	Worry $\beta = 2.55$	Worry $\beta = 1.95$

^a β is the partial slope averaged over both seizure groups and all visits; β_0 is the partial slope in the group without additional seizures averaged over all visits; β_1 is the partial slope in the group with additional seizures averaged overall all visits.

^b AS=additional seizures